

Date: 09/04/2024
Your Ref:
Our Ref: 8522

Enquiries to : Richard Mutch
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Dear

FREEDOM OF INFORMATION – GLYCOGEN STORAGE DISEASE

I write in response to your request for information in relation to Glycogen Storage Disease.

Question:

Specific to the time period between April 2018 until March 2024. Please break the information down to year-on-year i.e. 2018/19, 2019/20, 2020/21 etc.

- What training on Glycogen Storage Disease was available to NHS Lothian general staff?
- What training on Glycogen Storage Disease was available to NHS Lothian specialist staff?
- How many staff took part, which department they came from and when they took part in the training.

Answer:

All people with glycogen storage disease who are resident in NHS Lothian are looked after by the Scottish IMD Service, which is nationally commissioned and managed from NHS Greater Glasgow and Clyde (GGC). No training specific to glycogen storage disease has been given to non-specialist staff in NHS Lothian in the years specified.

The formal teaching about children is provided by me for the University of Glasgow and informal education is within the Scottish IMD Service (a nationally commissioned service managed by GGC). This is for both specialist and non-specialist Paediatricians.

Question:

- Please include any evidence or copies of training programmes available to NHS Lothian staff or metabolic specialist staff on Glycogen Storage Disease.
- Please include any evidence of completion.
- What information or resources or other learning materials are available NHS Scotland/Lothian staff on glycogen storage disease, of all kinds or each kind?
- Please include all copies or evidence of policies, guidelines and care pathways, any material that NHS staff have access to that would be used to inform or upskill staff specifically on Glycogen Storage Disease.

- What is the policy on assessment and treatment of each form of glycogen storage disease?

Answer:

As above please refer to the Scottish IMD Service as this is provided nationally.

I hope the information provided helps with your request.

If you are unhappy with our response to your request, you do have the right to request us to review it. Your request should be made within 40 working days of receipt of this letter, and we will reply within 20 working days of receipt. If our decision is unchanged following a review and you remain dissatisfied with this, you then have the right to make a formal complaint to the Scottish Information Commissioner within 6 months of receipt of our review response. You can do this by using the Scottish Information Commissioner's Office online appeals service at www.itspublicknowledge.info/Appeal. If you remain dissatisfied with the Commissioner's response you then have the option to appeal to the Court of Session on a point of law.

If you require a review of our decision to be carried out, please write to the FOI Reviewer at the email address at the head of this letter. The review will be undertaken by a Reviewer who was not involved in the original decision-making process.

FOI responses (subject to redaction of personal information) may appear on NHS Lothian's Freedom of Information website at: <https://org.nhsllothian.scot/FOI/Pages/default.aspx>

Yours sincerely

ALISON MACDONALD
Executive Director, Nursing, Midwifery and AHPs
Cc: Chief Executive